

**Medical Home Phone Conference**  
**January 23, 2007**  
**“Parent Advocates”**

**Attending:** Nancy Johnson (Cherry Tree in Utah County), Brandi Iverson (Dinosaur Land in Vernal), Laura Oppermann ( Budge Clinic in Logan), Maria Wiscombe (American Fork – Glade), Dana Ross (Redrock in St. George), Lisa Wade (Sandy), SunDee Lasko (American Fork – Connor), Amy Steadman (West Jordan – Terashima), Al Romeo, Barbara Ward  
**Gina Pola-Money**

**Gina Pola-Money:** Facilitated discussion to have the parent partners on the call share ideas and information about what is happening in their practices.

**From Lisa Wade:**

- Have a Medical Home Newsletter for the physicians to pass out to any of the appropriate patients. The first newsletter introduced Medical Home and the parent partners. The doctors picked a topic to write a little blurb about, as well. We have done the newsletter every quarter. Sam, the other parent, has written articles from her perspective as a parent of a 26 year old because she has gone through quite a bit and has written articles on what its like to get a diagnosis and what the education system was like.
- We meet as a medical home team once a month to discuss different topics and provide the parent side of things. They talk about the medical viewpoint or what concerns the practice, but we also talk about what is beneficial for parents.
- Each parent advocate is assigned their own phone line and message numbers so doctors can refer their parents to us. It’s not used as much as we would like but it is still a nice avenue to have. When I’ve contacted parents I can say that they can call that line so that I do not have to field calls at my home when it may or may not be convenient. Its still relatively new and we’re all trying to figure out how we work together as a team to make everything work. Kathy Heffron, who is our care coordinator, talks to the families and refers them to us. The doctors are not quite as trained to use that option but we’re working on it.

**Laura Oppermann:**

- Parent phone calls really come and go. Sometimes I’ll get a whole bunch and then I won’t get anything for almost a month. So it really varies. I’ve been involved with it for a while now.
- We have done a bunch of different things. We’ve done some family activities that have been quite fun and we’ve really had success with it. We done breakfast, swimming, playing, and picnics activities. We send out flyers to everyone identified in the Medical Home and we usually want an RSVP so we can guess on numbers. It’s been fun. Every time we’ve done it we have had different families come out so we’ve tried to find different things that will appeal to different needs and wants.
- We’ve just had our first informational evening meeting, which was okay too. I was concerned about response but we had some good turnout. We may continue that a bit more.
- One of the last parent meetings we scheduled two rooms so the adults were in one room and the room right next door to it was where we had the kids. Jessica and I invited our respite

workers so the parents could experience respite workers there. It turned out pretty well and we had a least half the families bring their kids.

- We also have trouble getting a response and getting families to fill out the forms to for the medical summary. One idea maybe to have the families talk about how helpful the medical summary has been for them, talk about how they use it and how it has been beneficial and put that in a newsletter, then families could see that this could be a good tool.
- Most families want information about resources or they are having trouble with something and they want some more information. The care coordinators will refer families to the parent partner to provide support or information. If the family agrees to have Laura call then she will get in touch with the family with the information they need.

**Amy Steadman:**

- We meet twice a month as a medical home team. We typically have one family per month and focus on their needs as a team. We meet in the evening and invite the family and provide some refreshments or dinner. Dr Terashima is a sole practitioner, so it's a small office but it allows us to be on a more personalized level. We are able to discuss their needs and find out what will help them the most and everyone is assigned a little something to work on before the next time that we meet together and our next meeting will be just the team. We will talk about some of the things we have found and how we are able to help the particular family and their needs.
- We also do, once a month, a "parent's time out." It is a night for families with a child with special health care needs to come out and it may be informational or it may be just a chance to network. Typically we have a topic so they feel there is some justification for taking time out to go. We are going to play with the idea of an afternoon and/or alternate afternoons and evenings.
- Jodi Hansen (the other parent partner) and I played with the idea of providing some kind of daycare nursery type thing but being a sole practitioner there is not really funds and it would have to be somebody who would volunteer their time and depending on the needs of the children that would come we found it would be difficult but that was not ruled out as a possibility or a least a need we knew about. We just don't know, being a small practice, if we can meet that need to get the parents out. At the family meetings they bring the children with them or at least the child we are discussing. Sometimes that has been good to see them in a different setting, other times it been a distraction. But all in all it has been positive. But for the "parent's time out" we haven't been able to provide it, but the two times we've had it the children were left with somebody at home.
- We send a quarterly letter out to each of those identified children with special health care needs. We list what the next three upcoming topics will be. For those who have participated they have been very grateful and want more.
- We have also done some focus groups and we've talked about the idea of having different parent groups, depending on the child's diagnosis and have more of common ground for the parents.
- We've also sent out questionnaires in the past to parents of children with special health care needs on what they would like to see.
- March of 2006 we held a bullying focus group, particularly bullying in school and invited several parents. We had 13 parents show up to that focus group. We are now working with others from the State Office of Education, URLEND, the Utah Parent Center and others to develop bullying information sheets that can be given to the parents to help them identify the

process of where they should start, who they should talk to and where to go from there if they are not satisfied with the outcome.

**Gina Pola-Money:**

- The parent partner at SouthRidge wants to put key information about bullying into their new parent information resource center. The information developed by Dr. Terashima's Medical Home will be valuable to them.

**Brandi Iverson:**

- We had a focus group for all the parent of micro preemie babies, we have 12 micro preemies in our practice. We did a focus group for them on RSV awareness and protection, and that went over well. We were able to make it mandatory so all the parents could be aware of that and receive the injections and that kind of thing. But it was nice as a parent to share my experiences of preventing RSV and being on lock down for three years every winter. So it opened the door for me as a parent advocate to have those parents trust me enough to call with questions and for resources. We are working on a new letter, but nothing has transpired other than that.

**Dana Ross:**

- One of the things we have done is have a luncheon with our families. We provided pizza and respite for the siblings if anyone wanted to bring the siblings. The luncheon included the parent advocates, the parents with children with disabilities, all the doctors and medical staff were there. It was an hour and a half long so parents could ask any questions. That went over really well and we are thinking of doing that again.
- We are also working on getting a medical equipment storage facility, since there isn't one set up in St George as of right now. We are working on getting a place where we can start putting all of people's unused medical equipment in storage so that other families can use it.
- I am also on a local chapter of Family to Family so we network the two groups together. We invited their staff and the medical home coordinator to an event we had. We rented out a movie theatre for families to bring their kids. We had a movie party that was really fun. I think it was great for families who don't get the chance to take their kids to the movies and be able to come and relax.
- When we had our luncheon, one of the main concerns from our parents was getting respite for their children. Even sometimes when people get services to get respite its hard to find people who can provide those services so our practice is working on one night a month where our parents can bring their children to our medical office and two of the staff have volunteered to watch the children for two hours so the parents can go out to dinner or run errands or just have a little bit of a break.
- I have parents call me at home and I've had a couple of phone calls from referrals the doctors have given them.

**Maria Wiscombe:**

- In our office we do what we have to do. Being involved with the Family to Family Network I get them the information from those support meetings and every year we try to have a behavior management training, which is always quite successful, which we set up through

Mary Ann Hunt. She has a grant that allows her to go throughout the state and provide these trainings free to the families.

- We are going to put together a new list serve for the family advocates/parent partners involved in Medical Home.
- I am almost done with the newsletter template. I am trying to gather some information. I know a lot of practices hand out a brochure to the families that describe Medical Home. We could highlight that information again bit by bit in the newsletters if that is helpful. We will also highlight different information, and different resources to use.

**Gina Pola-Money:**

- A key reason for having a list serve is because we get exciting new information and resources that is sometimes time sensitive. We want an easy mechanism for everyone to know about upcoming events and new information to get out to families. We are really trying to find ways to get information out but overload anyone.

**Sun Dee:**

- An idea would be to have a place on a website where there could be something like a Blog to get information out. There are so many support groups that it's hard to email families when things come up. It could alert if there is a conference coming up and a reminder to register, or whatever activity it is. There could also be commonly used links like DSPD or SSI.

**Nancy:**

- I'm still fairly new at this. We did have a parent luncheon scheduled but had to cancel because the doctor was on call. So we are rescheduling. I am impressed by the newsletter idea and I think that it's something that people with children who are a little older could really use. That is something I am going to press forward with.

**Gina Pola-Money:**

- Tiffany Home could not be on today because she is in class. They just had their second parent meeting at their practice. It was an afternoon meeting with lunch provided for the parents and they brought their kids. Gina and Sandra were invited to attend and provide a short presentation on insurance and financing. It was very informal with a lot of questions answered and a lot of information back and forth.
- Gina and the Medical Home team are more than willing to provide this information or any other topic that is requested to any of the practices.
- It is important to keep close contact for all of us in the Medical Homes to share ideas and experiences. We will look at setting up phone conference for just the parent advocates to share new information and resources as well as to bounce ideas off one another. We value everyone and their time so we will keep it short and simple and aim for about 45 minutes.